

Concurrent Session Two – Data Collection, Reporting, and Quality Assurance

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The same presentations were delivered at the beginning of Session Two on Data Collection, Reporting, and Quality Assurance as were offered during Session One with Xiahong Mao-Davis reporting this time on the CDC requirements for data collection, quality assurance, and data reporting; and Cynthia Prather reporting from the Science and Application Team. Hope Cassidy-Stewart again delivered the presentation on the State of Maryland Department of Health. The discussion following the overview presentations included:

Discussion Summary:

- ❖ An audience member said that she had just moved into a state that needs a great deal of help, and she was not sure that the staff and the computer system were prepared to deal with the Evaluation Guidance. She inquired as to whether someone from CDC could come to the state to help them put the software in place, and show them how to operate it. Choi Wan answered, saying that the ERAS system would be pilot-tested in eight different health departments during which time they would learn what kinds of training and technical assistance might be required. He assured the group that states would be able to use the system.
- ❖ Tim Quinn commented that there should be a mechanism whereby CDC staff can help state health departments with installing software, working with staff to get them familiar with the software. Choi Wan clarified that as ERAS is a Web-based system, no software will need to be installed. They will conduct pilot site workshops, through which they will incorporate feedback into the guidance materials that accompany the ERAS. These workshops will tell CDC whether the materials will be sufficient to help states navigate the system. Technical support will be available around-the-clock for the system. If the documentation is not at a stage where it can explain the system without training, then they will adapt their approach.
- ❖ An audience member commented that manuals are often not the best way for people to learn a new computer system; working hands-on is better. Some of the organizations in her state are at a very low level of technical capacity, so they will need some kind of training even to access the Internet. The time that they have before the system is up and running should be enough time for them to make training plans, such as courses at the

state college, so that their CBOs will be ready.

As in the first session, Tim Quinn divided the larger group into three smaller ones. This group handled their discussions somewhat differently than the groups in the first session. Each attendee was asked to write his or her most pressing question about data collection on a 3 x 5 index card, then each smaller group deliberated one of the questions. Each group's question is shown followed by its respective discussion.

Question #1

"Concern: with any policy, its power/application is realized through its implementation. I find it unethical for CDC to establish directives with no support: CDC should provide, via contractors, health department on-site TA whenever possible." The writer of the question clarified his statement, saying that sending manuals to health departments regarding directives does not ensure that the departments understand what is expected of them. Without on-site help, they cannot perform as well as they would like. What support can they offer states that do not have computerized, statewide reporting tools?

Discussion Summary:

- ❖ There was discussion about using CDC consultants to offer advice on the entire health department structure, not just on the Evaluation Guidance. For instance, CDC could help the state epidemiologist integrate data with the HIV prevention branch. Hope Cassidy-Stewart agreed that there might be an opportunity for an integrated system, and that there was no way not to have a consultant.
- ❖ A group member commented that another RFP was addressing that issue, which he thought was sponsored by NASTAD and CDC.
- ❖ Tim Quinn pointed out that some states have such small staffs that their operations become a question of what to give up or let slide in developing a system, and outside help is crucial.
- ❖ Hope Cassidy-Stewart wondered whether a consultant from CDC could come to such programs to assess their data system and needs, and to offer assistance where there are separate reporting systems for different branches of the department. States should integrate care and prevention. They are separate in Maryland, and a model to help them work together would be wonderful, she said. Mr. Quinn made a note of the question, indicating that he would take it back to CDC.
- ❖ There was discussion of the listserv, which could be a great resource for state health

departments to share information and build on their body of shared knowledge. These e-mail lists are relatively easy to manipulate and to filter, so departments can only access the information that they need. The NASTAD website also has links to many state health departments, it was noted, and CDC could include a similar section of links on their website. Tom Creger agreed that one of CDC's responsibilities is to keep abreast of such things.

- ❖ Hope Cassidy-Stewart remarked that NASTAD is under-utilized. She had not known that peer-to-peer health department TA was available. She suggested that perhaps the CDC listserv could include a message board and chat room. If information is archived on the site, then it can be reached easily. Forms could be included in .pdf file format as well.
- ❖ Another group member added that web-broadcasting is more cost effective than video-conferencing, and could be another great asset to them as they stay informed. It was also mentioned that this technology is aimed more at health departments than CBO's, but that some web-based applications might be appropriate for CBO's to use, with proper training, both on-site and via tutorials.

Question #2

This question focused on the realism of supervising the collection of good data from agencies when people are working for low pay and low benefits and are over-burdened in other areas. The reporting system's accuracy relies on good data at a micro level, and the ongoing interventions have standards. The questioner mentioned that in pilot-testing forms in four different places, his group got four different responses to them. Each state needs to personalize the forms, because certain formats and issues apply more than others. The field workers must have some system of supervision to ensure quality data.

Discussion Summary:

- ❖ Tom Creger agreed that a data system is only as good as the person collecting the data, and to achieve buy-in, the first person who needs to approve of the system is the person who is interacting with the population, conducting interventions. One of the benefits of going to these people for feedback is that they remind CDC of the behavioral change issues that are sometimes lost in the more "academic" approach to data collection. At CDC, he said they are advocating for forms that will be used, and used correctly. Step #1 is helping CBO's understand why they must collect data in a standardized manner. Then, they can move to more thorny data collection issues. He noted that all attendees of the conference seemed to be struggling with similar issues.

- ❖ A participant mentioned various public health models that incorporate extensive training programs in the field. Different states have different standards, and a particularly successful program utilizes role-modeling. So often, workers hired to do HIV and AIDS interventions on the street lack training and supervision, even though they are well-meaning people. Graduate students can provide a motivated pool of potential workers. Tom Creger commented that sometimes people can be instructed to fill out forms in a certain way and observe certain procedures, but they will not. Instead, they might give incomplete or incorrect information. Experienced field staff understand this issue.
- ❖ A group member commented that in training workers, it is also possible to establish an ongoing dialogue with them. Some states are creating requirements for certifying workers before they go into the field. She wondered if anyone else had experienced certifying outreach workers creating a baseline of good, prevention workers. Tom Creger agreed, emphasizing the important step of getting buy-in from the field workers. The Prevention Program Branch has struggled with that issue, he said, and he wondered how others have coped with it.
- ❖ Giving fast, specific time frames for when data reporting – forms give workers more accountability, and the forms can be tracked more closely. When deadlines are early for forms, there is less likelihood that the workers will fill them out in a hurry, right before they are due.
- ❖ Another participant described a long process of dealing with the issue of training and buy-in of workers. Regional training sessions were a way for them to work directly with programs in areas such as quality of care, definitions, activity types, and data collection. She also said that her department studies the data to find rationales for why certain types of information are sought in a given area. They can then respond to that demand by sending workers who appeal to the needs of the population. They have found greater receptivity to the forms, and fewer errors, by paying attention to these needs. Retention of staff is another issue, so she deals directly with program managers who can teach new staff how to fill out the forms so that they become institutionalized. It is also important that members of the target population see the forms and provide feedback. In general, they try to conduct quarterly assessments wherein they look at projected figures for the year and assess each program's progress. Sometimes the outreach workers need to be challenged about some data, but they are understanding more and more clearly the need for quality data and they understand that their role is central to creating an overall system that helps their target population.
- ❖ A participant commented that his department is always looking for good venues to use to educate their workers, and often a one-on-one discussion has been successful.

- ❖ Hope Cassidy-Stewart remarked that when they set out to create their data collection system, the Health Department Evaluation Guidance acted as a justification. They knew that they wanted to evaluate their prevention programs, but they never had the internal support they needed, so the data meant little. It will take them years to get data that is worth analyzing, but they have been inspired by the buy-in just from the first year of implementation. Their Community Planning Group members are very interested in sitting on the Evaluation Committee. They are, in fact, beyond initial buy-in. Now their CBO representatives are helping them refine their forms.
- ❖ Reports back to the agencies are key, said another participant, as they receive something for their efforts. Tom Creger agreed, and suggested that health department staff ask agency representatives questions about their reports so that they will see how carefully the data is used and discussed.

Question #3:

The Outreach Prevention Model includes the use of peers; however, bringing in peers creates problems with certification. Training is important, but after they are trained, then at what point are they no longer “peers?” They may lose their effectiveness in the population. There will always be slippage with outreach issues, so using these models is important: there has to be way to calibrate the context of the outreach.

Discussion Summary:

- ❖ A participant asked whether people would object to certifying outreach workers, and another asked about what happens to the smallest CBO’s that do not have the resources to make large changes in their labor pool.
- ❖ Hope Cassidy-Stewart said that Maryland has a diverse group of vendors and organizations that work at the grass-roots, and need help in a variety of areas. Her department took away their burden of data entry because they did not want to scare away those small CBO’s that have such a connection with the community but are “afraid of computers.”
- ❖ A participant said that the overhead salaries and benefits for a basically trained person are more than worth the expenditure, especially considering the impact on the services. Perhaps larger groups can contract out to smaller ones for this assistance.

Question #4:

Client-level data: how do you capture it, and what do you use it for? How do you capture risk

assessment, and how are clients kept anonymous?

Discussion Summary:

- ❖ The group acknowledged the difficulty of this issue. Some departments do not collect client-level data and concentrate on aggregate data.
- ❖ A participant pointed out that the main concern with this data is HIV status. These clients are not likely to be unique to one agency, but do not have the same identity to each one, even to multiple agencies within an agency.
- ❖ Hope Cassidy-Stewart described Maryland's method for creating unique identifiers. She acknowledged that it is not a perfect system, because there is some overlap. Clients must not feel at any point that they might be identified.
- ❖ A group member asked Hope Cassidy-Stewart about the feasibility of using data systems to see if clients reached through outreach are accessing other services and then trying to look at the possible linkages. She replied that they did not feel that outreach workers were willing to ask the amount of information that would be needed to link clients. They do not want to breach the relationship between the client and the outreach worker.
- ❖ One participant outlined a program that made clients "members," giving them an access card which would keep track of them when they used the Center's services. They saw a benefit of participating and being involved. So far, this program has relied on peer influence, and it has been a sought-after program with a high number of cases. Another person commented that her department had tried a similar management system because their clients were very mobile. Clients were assigned a card with a number at whichever venue they accessed, and that number was uniquely theirs at any point in the system. This method motivated a typically disenfranchised community, she said. Another member noted that in his experience, in a small community, the risk of identification most certainly keeps people away from programs.
- ❖ Tim Quinn noted the form's ability to capture new interventions, given that there is a place to explain new interventions on the form. Using these miscellaneous interventions gives agencies creative opportunities to try out new ideas. Hope Cassidy-Stewart added that those interventions are often difficult to measure. They are involved in coalition-building, and they are struggling to evaluate its impact and benefits, and how to make concrete connections to HIV risk behaviors.

Question #5

This question regarded borrowing ideas from other disciplines; for instance, from Prevention Case Management. What if there were a program announcement that would support the development of an intervention with prevention case management as part of the culture?

Discussion Summary:

- ❖ Tim Quinn pointed out that program announcements and projects are often dictated by Congressional mandate. Hope Cassidy-Stewart added that data has an impact on those mandates. Tim Quinn agreed, adding that there are good people and good resources in the field who are using their best efforts to conceive of the best processes. He reminded the group that any data collected that is not needed on CDC's aggregate form should still be kept for possible future use.
- ❖ A group member commented that his state has contractors that are conducting activities that do not necessarily fit into an intervention plan, such as focus groups. Definitions become a problem in this case because what the contractor calls a "focus group" often turns into a "discussion group" or an "educational session." How can he collect this information? Are there other means of reporting data collection on process objectives? Hope Cassidy-Stewart confirmed that they collect more data than what is required because they try to think about what the state needs, what the vendors need and want, and what CDC needs. She advocated for collecting "what you think is important," keeping in mind that the information can be categorized later.
- ❖ A participant pointed out that there is an inherent "Catch-22" in collecting and reporting extra information. If a small amount of money is allotted to a project, then the extra work and information may not be easy to get from vendors. Tim Quinn expressed his hope that they would want to provide all of the information that they get.
- ❖ A participant agreed that collecting more than the required characteristics is advisable for several reasons, including protection. If the model changes in the future, then the system can anticipate different data needs so that the "old" data is not lost in a "compatibility crisis." Tom Creger pointed out that the data can always be collapsed and then reported in subgroups.
- ❖ A participant described his department's transition from collecting very detailed, client-level data, with detailed assessments, interviews, and risk assessments, to collecting on an aggregate basis. Now they are collecting individual-level, client data as well as aggregate, outreach data.

Question #6:

This question regarded on-line video and whether anyone was using a specific tool for outreach to multiple risks, multiple times.

Discussion Summary:

- ❖ Hope Cassidy-Stewart said that their outreach does not track multiple encounters with the same person. Another group member tried to track this information, but said that it is difficult to ask about prior contact with an agency. Tracking the referral system is even more difficult.
- ❖ Tim Quinn urged the participants to use their Project Officers as resources, and to feel free to ask questions. He also encouraged them to use their colleagues as resources as they all worked through the Guidance together.